

Update on the Status of the Genetic Information Nondiscrimination Act of 2005
(S. 306/H.R. 1227)
Frank Swain

MS. BERRY: All right. The next order of business is really to proceed to today's agenda. The issue of genetic discrimination will be the first item of business. As you all know, those of you who have been following this committee's work, the issue of genetic discrimination, health insurance and employment has been really our top priority.

We have been closely monitoring federal legislative activities on the issue, and in May the committee sent Secretary Leavitt a compilation of public comments, a DVD of testimony that we heard last fall highlighting various public perspectives on the genetic discrimination issue, and a legal analysis of the adequacy of current law.

These three items were also disseminated to the public through the committee's website. This morning we will hear an update on the status of federal genetic nondiscrimination legislation, and a report on public attitudes about the privacy and misuse of genetic information.

Sharon Terry is here today representing the Coalition for Genetic Fairness. As many of you know, she's also President and CEO of the Genetic Alliance, an international coalition -- oh, Sharon is not here today. Frank? Where is he? There he is. Frank Swain. He's already seated at the table. Frank will be standing in for Sharon with the Genetic Alliance.

MR. SWAIN: I don't have slides.

MS. BERRY: You don't have slides? Okay. Well, thank you very much, Frank, for joining us this morning and for standing in. We appreciate it. With that, we will turn to you.

I just ask members of the committee that unless there are specific points of clarification, let's hold our questions until after all the presenters have completed their presentations.

MR. SWAIN: Well, thank you very much. It's a real pleasure to appear officially before the committee. I've been able to monitor the last two meetings here at least, and am very aware of the committee's strong interest in this legislation.

I told Sharon, who emailed me about 11:48 the night before last and said could I do this for her, for some odd reason, I was looking at my Blackberry when that came in, so that says something probably odd about both of us. I said certainly, but I would be a pale imitation for those of you who know Sharon. She's a whirling dervish in this issue area, on a broad set of issues. It's a real honor to represent her and her coalition.

We will do Q&A in a little bit under the schedule. Anything that I mention, I'd be happy to try to respond to to the extent possible and appropriate.

Let me review the bidding briefly. Our law firm has been working with the coalition for about eight months now to give additional push to this legislation, which as was mentioned, has been a concept around for quite awhile.

The legislation that has been introduced in the House of Representatives is H.R. 1227. It is a bill that essentially has two titles. One of the titles would prohibit the misuse, that is the negative use

of predictive genetic information about an individual in the employment context. The second title would do the same, prohibiting the negative use of predictive genetic information about an employee in the health insurance context.

This legislation, as introduced, is identical to legislation that was passed by the U.S. Senate in February, 97 to nothing. Unfortunately, the House is not about to pass it to 97 or 497 to nothing. There is significantly more controversy about the legislation in the House of Representatives this year, as there has been in each of the past Congresses for the last two or three sessions of Congress.

The two titles of the bill are assigned to two different committees. The employment title is assigned to the committee that has jurisdiction over labor matters, the health insurance title is assigned to the committee that has jurisdiction over health insurance matters and other insurance matters.

Additionally, some parts of the bill must be reviewed by the Ways and Means Committee, because it affects indirectly at least the Medicare program, and the Ways and Means Committee has jurisdiction over the Medicare Program. So we have a procedurally challenging project to get everybody moving forward hopefully at the same time, and in the same direction.

As I'm sitting here this morning, the bill has 150 cosponsors. The primary sponsor is Congresswoman Judy Biggert from suburban Chicago, and a more energetic and committed sponsor we could not find if we had perfect hindsight. She is marvelous. She is aggressively bringing in many of her fellow Republicans who she corners on the floor of the House and essentially twists their arm into signing onto her bill.

She knows what she's talking about. She is a lawyer who has practiced employment law. She also is a member of the House Science Committee, and has been significantly involved in the discussion at the Science Committee reviewing the progress of the Human Genome Project and the funding that went into that, and continues to go into that project. She speaks very directly and very sincerely when she says it is really silly for us to have invested hundreds of millions and billions of dollars of taxpayer money that we have in unraveling the human genome, and have everyone afraid to look at it.

I won't preach to the choir about the need for this bill. I will try to discuss some of the issues that we've come up against. First of all, the 150 cosponsors is significant. I recall back in March, the bill had not yet been introduced. Indeed we were on the cusp of having it introduced, and you folks were pressing us fairly hard about what is going on, and we really couldn't say anything because it is really not appropriate to do it until the member sponsors it. But it was introduced I believe on March 10th with 40 cosponsors.

When I attended your June meeting, it had about 80 cosponsors. Today it has about 150. On that basis, in about two more meetings, we should have the entire House cosponsoring it. But unfortunately it probably won't just run geometrically from here on out.

The issues that we are dealing with are primarily issues raised by the business community, some parts of whom have significant apprehension that the bill will make it unduly easy to challenge routine workplace decisions using the hook of genetic nondiscrimination. Or to be more blunt, if negative action is taken against an employee, an employee is feeling litigious, he or she may say, you're discriminating against me on the basis of gender, ethnicity, religion, or age, and now add genetics into the alphabet soup of claims against the employer.

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That is the fear of some. Not all by any means, but of some in the employer community. That is one of the issues that we are trying to work through to make sure that the bill is clearly written, that it clearly does what it is supposed to do, and does no more than that, that the bill is not some vehicle to bootstrap a solution to every perceived issue with our health delivery system.

There are those who say well, if this bill is passed and everybody is found to have some sort of genetic defect, this will somehow inevitably march us towards national health care. I don't understand that logic myself, but we hear that with some regularity.

We hear some other issues that are more mundane and more solvable. For example, there are a significant number of individuals in this country who do receive insurance through single life policies. That is, they are not members of groups. They buy their health insurance in the individual market.

In the individual market, there is clearly medical underwriting. You can't be in the individual insurance market without having medical underwriting. Part of medical underwriting in most cases, and I think this committee is well on record, as are many groups, in favor of family histories. You go to a doctor, and if the doctor is a good doctor, that doctor spends some time taking a family history.

Somebody says well, the family history is in effect a genetic history. So does that mean that if we use the family history in some decision, that that is therefore a violation of H.R. 1227? Well, we are saying clearly not. We want to promote family history.

Well, what's the difference between saying that somebody had several siblings with cystic fibrosis and having a genetic test that says that the cystic fibrosis gene is present? Well, those are the kinds of issues that we're trying to work out at this point. They are in my view, legitimate issues, and in my view, we're well on our way to working many of the important issues out.

At some point obviously we'll just draw a line in the sand and ask our sponsors to go out and get the legislation up and scheduled.

We are involved in informal but I think useful discussions with the U.S. Chamber of Commerce, the National Manufacturers Association, and some other groups that have had some traditional concerns about this legislation. It would be inappropriate for me and premature even if it were appropriate for me to say what the Chamber and the NAM are eventually going to do. I don't know what they're going to do, but it is at least a positive that they have agreed to sit down and talk with us and see if something can't be worked out on issues where there seems to be disagreement.

Finally, I might add that it is very important, the work that this advisory committee does candidly in urging the Secretary to take the positions that they must take. The administration thankfully is very strongly on record in favor of this legislation. But we need active advocacy at every level within the administration, within the scientific community, and within the business community.

Perhaps I'm being more candid than I should. One of the disappointments is that the business community, and in particular the biotechnology and the pharmaceutical community, have not really stepped up to the plate on this legislation, although many participants in that community would be very directly and possibly impacted if we could remove the apprehension that has been clearly documented in the public at large over having genetic tests and having genetic tests used in product and scientific development.

Finally, I might add there has been a very interesting case, situation, involving a professional basketball player, an NBA basketball player, who was with the Chicago Bulls. I'm not an expert by any means on the physiology of his condition or his alleged condition, but the Bulls said that they wanted him to have a genetic test because there was a concern that he had some sort of coronary condition that might result in his dropping dead on the basketball court.

He refused to have that genetic test. He has since been traded to the New York Knicks where presumably he will play basketball without a genetic test, or without at least publicly talking about whether he's had one or not.

The interesting thing, and this is a classic case of hard cases probably make bad law, and I'd be happy to discuss it further in Q&A if you're interested, because there are a lot of individual situations there. They are not clearly generalizable to the public at large.

But it has galvanized attention, at least in the mid west, on this issue. The Chicago Tribune has come out with an editorial endorsing this legislation, and has had a fairly interesting series of articles about this as a case study in what may happen and what employers might do in the future.

I'm not sure how far you can push it, but it is a vivid reminder of the sorts of issues that are out there, and the reason that we need a federal law to clearly set out for individuals that live in every state, not just in the 33 states that have state laws on the book, what the rights and responsibilities of employers, employees, and insurance companies are in this very important area.

With that, I will close my PowerPointless presentation.

MS. BERRY: Thank you very much, Frank.

Don't go away, because we'll have some questions and we'll enjoy hearing your views on the case that you just raised, and other matters.